Resources to Learn More

Angelini Pharma Inc

Our <u>dialysis infection control products</u> have been the standard of care for over 20 years in the U.S. and a century worldwide. With a portfolio of disinfectants, we offer alternatives across the care continuum that make preventing infection simpler to improve healthcare provider compliance.

Fresenius Kidney Care

<u>Fresenius Kidney Care</u>, a division of Fresenius Medical Care North America, provides kidney care education, dialysis treatment, and support services to more than 200,000 people with kidney disease every year both in home and at more than 2,600 centers nationwide. The company's dedicated teams help address the physical and emotional aspects of kidney disease through personalized care, education, and lifestyle support services.

Coping Support: Facebook Groups

Online groups can be a great source of emotional support for health issues. No two people—or treatments—are alike, though. So, what works for someone else may or may not work for you. Check all health tips with your care team.

Private Facebook groups: *only* members of the group can see posts. You cannot share posts from a private group. You may find these private groups helpful:

- Home Dialysis Central. Supports those who do—or might want to do—PD or home HD, and care partners.
 - www.facebook.com/groups/HomeDialysisCentral
- Chronic Kidney Disease Support.
 www.facebook.com/groups/CKDSupport
- Kidney Pancreas Transplant Support. www.facebook.com/groups/1599992600260062
- Kidney Support: Dialysis, Transplants, Donors and Recipients.
 www.facebook.com/groups/kidneytransplantdonorsandrecipients
- Peritoneal Dialysis Support Group www.facebook.com/groups/peritonealdialysissupportgroup

Public Facebook groups: *your friends* may be able to see your posts. You may want to join these groups to learn—but not post to them:

- Dialysis & Kidney Disease Support. www.facebook.com/DialysisandKidney
- Dialysis Discussion Uncensored. www.facebook.com/groups/DialysisUncensored
- Transplant Buddies Awareness. <u>www.facebook.com/TransplantBuddies</u>



Other Online or Phone Support

- **Family Caregiver Alliance**. Supports families who care for adult loved ones with chronic, disabling health problems. www.caregiver.org
- **NKF Peers**. Telephone support from others who have kidney disease. Call toll-free: **(855) NKF-PEERS (855) 653-7337**. Or, visit www.kidney.org/patients/peers
- **NKF Cares.** For those with kidney disease or a transplant, or organ donors. Trained specialist(s) listen to concerns. Call toll-free: **(855) NKF-CARES ((855) 653-2273)**. www.kidney.org/nkfcares
- **AAKP Support Groups** by state. <u>aakp.org/center-for-patient-engagement-and-advocacy/support-groups</u>
- VA Caregiver Support Program. Info on VA in-home and out of home services. There is a call line, peer support, workshops, and more. caregiver.va.gov/care_caregivers.asp

Non-Profit Kidney Advocacy Groups

- American Association of Kidney Patients (AAKP). A free membership group with a magazine, yearly patient meeting, and more. www.aakp.org
- **Dialysis Patient Citizens (DPC)**. A free membership group. DPC aims to improve quality of life. www.dialysispatients.org
- **Home Dialyzors United (HDU).** A national group to inspire, inform, and advocate for an extraordinary quality of life for people on home dialysis. www.homedialyzorsunited.org
- National Kidney Foundation. Info on kidney disease, guidelines, and more.
 www.kidney.org
- **Renal Support Network.** Info for patients, kids and parents, online support groups, Zoom meetings, podcasts, a yearly Prom, and more: www.rsnhope.org

Kidney Disease

- Kidney Glossary. Learn the terms you may read or hear when you get care for kidney disease.
 www.lifeoptions.org/glossary
- Life Options. Find out about symptoms, risks, how to slow CKD, and options if your kidneys fail—to have a good life.
 www.lifeoptions.org
- Learn About Kidney Disease Living With Kidney Failure Professionals Professionals Resource Library Kidney Glossary
- **MedlinePlus**. Info on health topics, meds, tests, treatments, and more. www.medlineplus.gov
- National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). Covers health topics, weight, diet, etc. www.niddk.nih.gov/health-information
- **National Kidney Foundation A to Z Guide**. Has the most popular NKF booklets for patients and clinicians. www.kidney.org/atoz

Kidney Failure Treatment Options

Transplant

- **Organ Procurement and Transplant Network (OPTN)**. Find a guide, brochures, and a helpline. www.optn.transplant.hrsa.gov/learn/patient-education
- Scientific Registry of Transplant Recipients (SRTR). Compare transplant programs. See data on living and deceased donor transplants by year. Look at programs near you vs. the U.S. average for wait time and 1-year kidney survival. www.srtr.org
- Transplant Conditions of Participation. The 2007 (still most recent) rules for U.S. transplant programs. www.cms.gov/Medicare/Provider-Enrollment-and-Certification/GuidanceforLawsAndRegulations/Downloads/TransplantFinalLawandReg.pdf
- Transplant Living. Helps you learn what to expect before and after a transplant. Info on living donation, costs, resources, kids, and support groups ("Community.") www.transplantliving.org
- **United Network for Organ Sharing (UNOS)**. Has national, regional, state, or program data by organ. www.unos.org/data/transplant-trends
- **Veterans Benefits Administration**. Help for veterans and their families. <u>www.benefits.va.gov/benefits</u>

Dialysis

- Home Dialysis Central. Reams of info about home options, living well, forums, equipment, and much more. https://homedialysis.org/
- Kidney School. Free learning center with 18 modules on topics from coping to sexuality. Visit live, read PDFs, or listen to audios. https://kidneyschool.org/
- My Kidney Life Plan. Choose the right treatment for you so you can feel your best and live the way you want to: www.mykidneylifeplan.org
- Ultrafiltration Rate Calculator. See how much water to remove safely during an HD treatment. homedialysis.org/ufr-calculator
- ESRD Conditions for Coverage. The 2008 (most recent) rules dialysis clinics must meet to be Medicare certified.
 www.cms.gov/Regulations-and-
 - Guidance/Legislation/CFCsAndCoPs/Downloads/ESRDfinalrule0415.pdf
- United States Renal Data System (USRDS). Annual report of U.S. data on CKD and ESRD (dialysis and transplant). www.usrds.org





Comfort Care

Hospice Care. Learn about all aspects of hospice programs.
 www.govinfo.gov/content/pkg/CFR-2020-title42-vol3/pdf/CFR-2020-title42-vol3-part418.pdf

Paying for Kidney Treatment

 Paying for Dialysis or Transplant is Kidney School module 18. Learn how Medicare and other programs can help you. <u>kidneyschool.org/m18/#</u>

Keeping a Job

Kidney Failure and Your Work Life. This a
Kidney School module covers how to keep
your job or get a new one, and where to
get help. www.kidneyschool.org/m17/#



- **AAATakeCharge**. Program provides up to \$14,000 to help people keep their jobs, set career goals, and become financially self-sufficient. www.aaatakecharge.com
- **AbilityJOBS**. Says it is the largest site for people with disABILITIES. All posted jobs are from employers who want to hire people with disabilities. www.abilityjobs.com
- American Association of People with Disabilities. Advocates for full civil rights for the over 60 million Americans with disabilities. www.aapd.com
- Americans with Disabilities Act. This site tells you which agencies enforce the ADA law for work, transportation, education, housing, labor, etc. www.ada.gov
- **CareerOneStop**. Build skills, search for a job, interview, disclose a disability, and more. www.careeronestop.org
- **Federal Employment of People with Disabilities**. Helps people find federal jobs. www.opm.gov/policy-data-oversight/disability-employment
- National Federation of the Blind Resources. Info on employment and resources to help people who are visually impaired. www.nfb.org/resources
- **NTI@Home**. Job listings for Americans with disabilities seeking home-based work. www.ntiathome.org/work-at-home-jobs-disabled.shtm
- Office of Disability Employment Policy. Resources for people with disabilities for many things, including work. www.dol.gov/agencies/odep
- Rehabilitation Services Administration (RSA). Oversees state vocational rehabilitation (VR) agencies. https://rsa.ed.gov/about/programs
- **Social Security Work Site**. Ticket to Work program and links to info for people with disabilities and service providers. www.ssa.gov/work
- U.S. Commission on Civil Rights. How to file a work discrimination claim. www.usccr.gov
- **USAJobs**. Lists jobs in the federal government. www.usajobs.gov

Insurance

- Health Insurance Portability and Accountability Act (HIPAA). Learn your rights for health insurance if you lose a job, change jobs, move, or get divorced. www.dol.gov/sites/dolgov/files/EBSA/about-ebsa/our-activities/resource-center/fact-sheets/hipaa.pdf
- **Health Insurance Marketplace**. Options for U.S. health plans when no other health plan is available. www.healthcare.gov
- Indian Health Service (IHS). Info on the U.S. health program for American Indians and Alaska Natives. www.ihs.gov
- **Medicaid**. Describes Medicaid and the Children's Health Insurance Program. Find overviews of each state's program. www.medicaid.gov/
- National Association of Insurance Commissioners. Info on ALL kinds of insurance, with links to each state's website. content.naic.org/consumer.htm

Help to Buy Prescription Meds

- CostPlus Drugs. Mark Cuban's drug discount site. www.costplusdrugs.com
- GoodRx. Coupons to save up to 80% of prescription drug costs. www.goodrx.com/
- **Needy Meds**. Info on drug pricing by zip code, drug assistance programs, drug discount cards, and more. www.needymeds.org
- RxAssist. Patient assistance programs by drug name and maker. www.rxassist.org
- **State Pharmaceutical Assistance Programs**. List of programs that help pay for drugs. www.medicare.gov/plan-compare/#/pharmaceutical-assistance-program/states

Paying for Transplant

- American Organ Transplant Association. Greyhound bus fare for transplants and info on other resources. www.aotaonline.org
- American Transplant Foundation. Fnancial, emotional, and education support to recipients, donors, and families. www.americantransplantfoundation.org
- Angel Flight. Free flights for health care for those who qualify. www.angelflight.com
- Medicare Coverage of Kidney Dialysis and Kidney Transplant Services. Booklet with basics about Medicare, paying for treatment, and where to get help. www.medicare.gov/Pubs/pdf/10128-Medicare-Coverage-ESRD.pdf

Paying for Dialysis

- American Kidney Fund (AKF). Small grants for patients, disaster relief, can help pay
 health premiums for those who qualify. www.kidneyfund.org
- **Benefit Eligibility Estimate Screening Tool**. See if you may qualify for Social Security. *This is not an application*. Info you enter is not saved. www.ssabest.benefits.gov
- **Benefits CheckUp**. Tool from the National Council on the Aging helps those 55+ find resources in their state to pay for health needs. www.benefitscheckup.org
- Guide to Choosing a Medigap Policy. Health plans to fill in Medicare gaps, what they
 cover, and your rights. www.medicare.gov

- Medicare Coverage of Kidney Dialysis and Kidney Transplant Services. Basics about Medicare, paying for treatment, and where to get help.
 www.medicare.gov/Pubs/pdf/10128-Medicare-Coverage-ESRD.pdf
- Medicare Start Date Calculator. Save thousands!
 Learn when Medicare can start based on which treatment you choose. www.homedialysis.org/homedialysis-basics/calculator
- Medicare & Other Health Benefits: Your Guide to
 Who Pays First. Learn how other health plans
 (employer, COBRA, etc.) work with Medicare.
 www.medicare.gov/sites/default/files/202110/02179-Medicare-and-other-health-benefits-yourguide-to-who-pays-first.pdf



 Social Security Administration. Learn about and apply for Retirement, Disability, Supplemental Security Income (SSI), and more. www.ssa.gov

Paying for Comfort Care

Medicare Hospice Benefits. Find out how to qualify, what is covered, how to find a
hospice, and where to learn more. www.medicare.gov/Pubs/pdf/02154-medicare-hospice-benefits.pdf

Other Resources

- **AMA Doctor Finder.** Find a specialist near you. https://doctorfinder.ama-assn.org/doctorfinder/
- **Eldercare Locator.** A U.S. government site to help find services for older adults and their families. www.eldercare.acl.gov/Public/Index.aspx
- **Medicare Care Compare**. Look up doctors, hospitals, dialysis clinics, nursing homes, and more. www.medicare.gov/care-compare/
- **Medical Equipment Suppliers**. Find local, state, federal, and private sources. www.medicare.gov/medical-equipment-suppliers
- MobilityWorks. Wheelchair vans and other equipment can make life easier. www.mobilityworks.com
- National Aging & Disability Transportation Center. Info on ADA rules, paratransit, elderly transportation, and more. www.nadtc.org
- **Smarter Travel**. Tips for travel for people with disabilities. <u>www.smartertravel.com/disabled-travel</u>
- **State Bar Associations**. Find a lawyer near you who works in the kind of law you need. www.generalbar.com/State.aspx